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ABSTRACT

This technical report is part of a series on AIDS/HIV (Acquired Immune Deficiency Syndrome/Human Immunodeficiency Virus) and is intended to help link various legal advocacy organizations providing services to persons with mental illness or developmental disabilities. Through a series of case examples, questions, background information, and resources for further study, this report is designed to assist with HIV/AIDS policy implementation. An overview of major federal laws and court rulings provides information on key federal disability policy issues, laws and regulations, and court rulings. Questions for discussion are provided for the two case studies. Definitions of major disability terminology as applied to AIDS (e.g., access to services, confidentiality, duty to warn) are also given. A checklist allows advocates to evaluate an agency in terms of: (1) HIV testing policy and informed consent; (2) confidentiality; (3) universal precautions; (4) intake and assessments; (5) access to services; and (6) education. Twenty-one additional resources are recommended. (DB)

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Strategies for Implementing AIDS/ HIV Policy Guidelines in Developmental and Mental Health Services: A Background and Checklist for Advocates

David C. Harvey, M.S.W.

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National Association of Protection & Advocacy Systems

The National Association of Protection & Advocacy Systems is the membership organization of 86 Protection & Advocacy Systems (P&As) and Client Assistance Programs (CAPs) located in every State and U.S. territory. P&A agencies for persons with developmental disabilities (PADD) were created by Congress as part of the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 94-103). In 1986, Congress added the Protection & Advocacy System for Mentally Ill Individuals (PAMI) (P.L. 99-319). The Client Assistance Program was created under Section 112 of the Rehabilitation Act of 1973 (P.L. 93-12).

P&As and CAPs are mandated to provide information and advocacy services including legal, administrative, and other appropriate remedies to protect the rights of persons with disabilities who reside in institutions, facilities, and other locations, and persons being served by state departments of vocational rehabilitation.

P&As and CAPs are increasingly confronting legal, policy and advocacy issues involving adults and infants infected with HIV, and a range of other issues associated with communicable disease policy, sexuality of persons with disabilities, and persons with dual diagnosis of mental illness or developmental disability and drug use. It is the hope of NAPAS that this series of technical reports will assist the field in responding to the newest challenge facing disability services.

Elizabeth J. Bauer, President, NAPAS (1990)
Executive Director, Michigan Protection & Advocacy Service, Inc.

Curtis L. Decker
Executive Director, NAPAS

Purpose of Publication

In 1988, NAPAS submitted a grant proposal to the AIDS Prevention & Service Program of the Robert Wood Johnson Foundation, Princeton, New Jersey, to develop AIDS legal advocacy services through technical assistance to NAPAS members and production of monographs and research articles. NAPAS was awarded a grant January 1, 1989 for one year, together with 54 other grant recipients nationwide.

Published in March 1990, this publication is the third in a series of technical reports on AIDS/HIV legal, policy and advocacy issues pertaining to mental health and developmental disability services. These technical reports are intended for wider distribution beyond Protection & Advocacy Systems and Client Assistance Programs to the disability and AIDS community, and are designed to help link various legal advocacy organizations in mutually beneficial and cooperative ventures. Although the responses and capabilities of agencies vary throughout the United States, these technical reports may provide assistance to others and can serve as guideposts for other organizations seeking to initiate or enhance similar efforts.

Comments and feedback on the usefulness of this technical report are welcome and should be addressed to David C. Harvey, Project Director, NAPAS, 220 Eye Street, NE, Suite 150, Washington, D.C. 20002, (202) 546-8202.

This technical report was researched and written by NAPAS staff member David C. Harvey, M.S.W., who is the Project Director of the Robert Wood Johnson Foundation AIDS grant. The author also wishes to thank the NAPAS AIDS Advisory Committee for assisting with the conception of this paper and review of initial drafts. The Committee Consists of:

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Strategies for Implementing AIDS/HIV Policy Guidelines in Developmental and Mental Health Services: A Checklist for Advocates

David C. Harvey, M.S.W.

This paper is the third in a series of technical reports on HIV education, liability, and policy development, related to mental health and developmental disability service systems. Through a series of case examples, questions, background information, and resources for further study, this technical report is designed to assist with HIV/AIDS policy implementation. The report is designed to provide quick accessibility to the complex legal and policy issues associated with HIV/AIDS, and lend strategies to detect whether implementation of guidelines has been effective in mental health and developmental disability services.

In addition, an overview of major federal laws and court rulings will familiarize persons not necessarily knowledgeable about key federal disability policy issues, laws and regulations, and court rulings. A practice scenario will also give the reader a chance to strategize how to best confront an actual problem involving persons with mental disabilities who also have HIV infection.

Having written policies in place that are designed to guide health service delivery procedures related to HIV disease and AIDS only meets the partial need of staff and clients of developmental disability or mental health service systems. How these policies are implemented is a crucial component to the delivery of services for people with disabilities.

This paper does not dictate what are appropriate policy guidelines or what denotes proper implementation. Sound policy development and strategies for implementation can occur only after a thorough understanding of the issues. Although this checklist can serve as a quick reference tool for advocates, actual policy-makers are cautioned to consult further references before devising any policy guidelines.

When viewing AIDS/HIV in the larger context of disability policy, many fundamental issues emerge for re-evaluation such as: informed consent, duty to protect or warn, confidentiality, patient management, access to services, right to sexual expression, abuse and neglect, and other issues. AIDS and HIV may prompt the disability field to redress prior inadequacies in these areas.

The following case examples will introduce you to dilemmas faced by clients and service providers regarding HIV disease and AIDS. You may find some solutions to the discussion questions following these examples by looking to federal laws and policy term definitions outlined in the next section of the paper. Following these sections, the checklist for advocates provides guidance for a detailed review of your local state or agency policies. Finally, a resource listing will give ideas for further study.

Case Study #1 _____

David is a 27 year old man with chronic and severe manic depression (bipolar disorder) residing in a state operated group home. David has a history of sexual acting out and has had a number of male sexual partners. At the urging of staff who were concerned about David's HIV status, he went for voluntary, anonymous HIV screening. Staff expressed concern about working with David if he was HIV positive and some staff threatened to not work in the group home with David. Upon the test results, David learned he was infected with HIV. He voluntarily told his counselor and the counselor informed the rest of the staff in the agency. A crisis erupted among the staff in the agency when certain staff members refused to work with David in the group home. The agency currently has no infection control policy, has instituted no educational programs for clients or staff about communicable diseases, and the Board of Directors voted in an exclusionary policy that denied admission to any future clients who were known to be HIV positive without consulting advocates or attorneys.

Discussion

1. Define how this agency might resolve this crisis.

2. Examine issues of discrimination in services and the Board of Directors decision to not admit clients with HIV infection.

3. Examine possible strategies for developing and implementing infection control policies, education and prevention efforts, and policies on confidentiality, with specific attention to who should be informed of a client's communicable disease status.

4. Discuss resources available to help resolve this crisis. Consider Protection & Advocacy legal services, local AIDS service organization assistance, or state departments of mental health or public health.

Case Study #2

A pre-school program for children with developmental disabilities wants to create a separate class for infants with HIV. The mother of a two year old wants her child placed in a regular class. How should the agency and parent handle this situation?

Discussion

1. What federal laws influence this service situation?

2. What resources does the mother have at her disposal?

3. How would you advise the mother to conduct herself in pursuing her objective?

4. What would you advise the agency in terms of policy development, implementation, and service design?

- Access to Services: Persons with disabilities have traditionally been discriminated against in securing needed medical, social and housing services. Adults, children and infants with HIV have similar problems. A variety of anti-discrimination protections through federal and state laws (as well as proposed legislation), ethical duty to treat, and tort principles of law may remedy problems in access to services.

- Advocacy: As a term with many different facets, advocacy incorporates the service improvement efforts and rights protection movement of "consumers" (who maintain the right of the buyer to quality services), disability civil rights activists, parents of persons with disabilities, and professional advocates who work through state Protection & Advocacy Systems, Developmental Disability Planning Councils, and University Affiliated Programs. Many different professions have advocacy components to their ethical mission and goals, and the on-line service provider in mental health or developmental disability services, as well as AIDS service organizations, are as much advocates for their clients as are federal policy-makers. As a hall-mark of the helping professions, advocacy is a central component of helping to improve the social functioning of an individual through protection of rights, obtaining needed services and benefits, and promoting self-determination.

- Community Based Services: A community integrated support model of responsible people and coordinated resources within a local, defined area, who provide social and health services to persons in need. Currently, over 800 community based AIDS service organizations in the U.S. now provide health, drug therapies, social and legal services for persons with HIV disease or AIDS. Some services for persons with developmental disabilities or mental illness follow these same models, with varying degrees of success based on jurisdiction.

- Confidentiality: As derived from the common law, the U.S. Constitution, state statutes, facility licensure laws, client-physician ethics, and the protection of civil rights— all are founded on principles of confidentiality. Breaches of confidentiality have led to discrimination and denial of services, especially in relation to HIV disease or AIDS.

- Duty to Warn: Considerations involving confidentiality are not absolute and courts have ruled in some cases, that disclosure of medical knowledge is outweighed by the need for the public good. However, it is unclear what responsibility service providers have for persons with developmental disabilities or mental illness who also have HIV infection, and who clearly and directly may pose a direct threat to infecting others through sexual or violent behavior and IV drug use. The law is more clear about the physician's duty to warn unsuspecting third parties.

- Guardianship: Through due process procedures, a court can appoint a representative to act on behalf of a legally incapacitated person. Guardianship issues have emerged around infants with HIV who are abandoned by their mothers in hospitals, child custody, and guardianship issues within child welfare agencies and foster care homes.

- Infection Control Guidelines: As basic policy guidelines that control the spread of communicable diseases, and educate staff and clients on infection control procedures, these guidelines may also minimize claims of liability from transmission through negligent actions. The best recognized source of information on appropriate infection control guidelines are developed by the U.S. Centers for Disease Control which published: "Recommendations for Prevention of HIV Transmission in Health-Care Settings" (see references for further study at the end of this paper).

- Informed Consent: Allowing persons with disabilities and their families who may lack decisional capacity the widest possible means towards self determination in treatment has always been a difficult issue for courts to handle. The presence of HIV complicates the need to obtain informed consent where medical procedures, HIV testing, concerns over possible worker exposure, and other treatment issues may be urgent.

- Least Restrictive Environment: This legal concept has been enlarged through the interpretation of courts, lawyers and others, to include educational settings, work settings and other program components. The concept promotes integration of adults, children and infants with disabilities (that includes HIV) in the mainstream of community life and services, and states that integration is an inherent right.

- Liability: Service providers have expressed concern about liability for damages from negligent transmission of HIV or dangerous other communicable diseases (such as hepatitis B) to workers or clients. At this time, it appears that claims of liability against facilities will be difficult to uphold in court because, in the case of HIV, its delayed onset of symptoms, statutes of limitation, and the difficulty of burden of proof. Claims of liability may be reduced by instituting universal precautions outlined by the Centers for Disease Control.

- Normalization: As a "developmental model" which promotes a belief that all people can grow and learn, normalization has encouraged the trend away from institutions and segregated services, toward integrated community services, including those serving adults, children and infants with HIV.

- Primary & Secondary Education: As a means towards first preventing disease or disability through behavior change aimed at minimizing risk of acquiring disease, primary education is mainly prevention. Secondary education involves providing the knowledge and tools to persons with a disease or disability who need to access services, manage their disease or disability, or empower themselves.

The following is a chronological history of disability law and court rulings. These do not represent all legislation or court decisions pertinent to persons with disabilities or HIV disease.

Some of the following information is adapted from Advocacy for Change Training (1985), by Christina A. Metzler, National Association of Developmental Disability Councils.

- 1963: The Mental Retardation Facilities and Community Mental Health Centers Construction Act (Public Law 88-164) passes. The philosophy of "deinstitutionalization" reaches a vanguard with passage of this legislation, which refers to an emphasis on treatment in the community and away from institutions. University Affiliated Programs were originally established under this legislation.

- 1965: Social Security Amendments (Public Law 89-97) establishes Medicaid-Medicare, which pays for health services for the poor, aged and disabled.

- Medicaid benefits under Title XIX of the Social Security Act and the establishment of the Supplemental Security Income (1974) program influenced use of both community services and institutions.

- 1973: Rehabilitation Act passes which significantly expands rehabilitation service programs and includes Section 504 which establishes civil rights protection for people with disabilities.

- 1975: Education for All Handicapped Children Act (Public Law 94-142) passes which enhances the rights of children with disabilities to an appropriate education and provides funds to states to provide educational services.

- 1975: Developmental Disabilities Assistance and Bill of Rights Act expands P.L. 88-164. Protection & Advocacy Systems are established as a required state program.

- 1978: The newly titled Developmental Disabilities Assistance and Bill of Rights Act changes the definition of developmental disabilities to a set of functional criteria. DD caused by HIV infections ultimately meet this functional criteria.

- 1984: The Developmental Disabilities Act is renewed with increased focus on "independence, productivity and integration"

- 1986: The Amendments to the Education for All Handicapped Children Act (Public Law 99-457) sharply increases the annual per capita allowance a state receives for each pre-school aged child with a disability.

- 1986: The Protection & Advocacy System for Persons with Mental Illness passes Congress (P.L. 99-319), adding provisions to the existing P&A for persons with developmental disabilities to include persons with mental illness.

- 1987: The U.S. Supreme Court ruled in School Board of Nassau County v. Arline, that a medical condition caused by an airborne infectious agent can be considered a handicap, under the meaning of Section 504 of the Rehabilitation Act of 1973. This is widely held as extending to HIV.

- 1988: The U.S. Department of Justice acknowledges the Supreme Court ruling and stated that people with asymptomatic HIV infection are covered under Section 504, as contrasted with full-blown AIDS.

- 1988: The Eleventh Circuit Court of Appeals in a case involving a child with developmental disability caused by HIV infection, Eliana Martinez v. School Board of Hillsborough County, rules that a process be set up whereby a determination is made about the most appropriate placement under P.L. 99-142 and, next, a determination of whether the child is otherwise qualified in the meaning of Section 504.

- 1988: The Fair Housing Amendments Act passes which protects persons with disabilities- including HIV- against discrimination in housing in the private sector. Regulations also govern providers of care in residential facilities.

- 1990: American with Disabilities Act, now before the U.S. Congress with passage expected this year, will provide anti-discrimination protection for persons with disabilities (that include HIV) in the private sector. (Passed Senate 9/89, pending House)

Suggestions for Advocates

The benefits of examining how a service system is coping with AIDS and HIV disease go beyond issues specifically related to this disease. An evaluation allows you to uncover system-wide issues related to access to health services, informed consent, confidentiality, and many other issues.

1. As a first step, request from your state's department of mental health, developmental disability, or vocational rehabilitation, written policy guidelines on management of communicable diseases and/or AIDS and HIV policy guidelines. If your state or agency has no written guidelines, write a letter requesting to know why none have been developed and offer to refer the personnel to appropriate resources.

2. Some state departments or agencies may have separate policy statements on HIV testing, confidentiality, medical treatment, etc. Make sure to request all relevant policies. Some of these guidelines may not be identified as AIDS/HIV specific, but may be designated as "health education guidelines", "infection control policy", or "sexual expression policy".

3. Next, ask the state department contact person or agency representative what resources they used in writing their HIV disease and AIDS policy guidelines. Did they use federal guidelines developed by the Centers for Disease Control, Occupational Safety & Health Administration, or a federal administering agency that oversees or provides funds to state departments or agencies (i.e., the National Institute of Mental Health, U.S. Rehabilitation Services Administration, U.S. Department of Education, U.S. Administration on Developmental Disabilities). What other resources did they use?

4. You may want to ask the state department contact or agency representative whether anonymous information is being compiled on the number of persons with disabilities who are also infected with HIV, have HIV disease or a diagnosis of AIDS. This may assist you with understanding how the state or agency is coping with HIV or AIDS related issues. Is the service system defensive and will not give out the information? Are there attempts to monitor this health issue within the disability population? Look for clues from other issues, such as sexual expression policy guidelines, which may give you a lead on how state authorities or management staff understand HIV related issues and how they are coping with them.

5. Once you have obtained the necessary policy guidelines or lack thereof, use the following structured questions to complete a detailed review. Are policies consistent with current scientific knowledge? Do they contain all the elements outlined below? If not, why not, and can you request that those areas be examined and policy guidelines be created that are sensitive to client civil rights, concerns of parents, and service providers?

6. Finally, remember that this checklist is only a introduction to the issues. You may need to research further into a specific issue and you may need to refer to local resources such as your community based AIDS service organization, Protection & Advocacy System, or other advocates. You may also need to consult your local public health department, disability attorney or physician. Be assertive and creative in the solutions to these complex legal and policy issues.

HIV Testing Policy & Informed Consent

1. Does the department of mental health, developmental disabilities, education or vocational rehabilitation have a stated policy on mandatory or voluntary testing? Is the policy consistent with state laws and regulations, some of which are specifically related to mandatory or voluntary testing?

   ☐ yes ☐ no ☐ needs more work

2. Are procedures adequate for mandatory or voluntary testing within institutions or facilities? Or are patients referred to anonymous testing sites or other locations for testing?

   ☐ yes ☐ no ☐ needs more work

3. Does the department or agency HIV testing policy have specific procedures for informed consent are they adequate?

   ☐ yes ☐ no ☐ needs more work

4. What comprises the actual release form for informed consent? Does it outline specific procedural steps for obtaining and giving informed consent? Does it match specific state requirements on informed consent through court proceedings, presence of guardian or advocate, or do procedures for HIV testing differ from other consent for medical procedures?

   ☐ yes ☐ no ☐ needs more work

5. Are clients or patients provided with pre and post testing counseling for HIV testing?

   ☐ yes ☐ no ☐ needs more work

6. Are clients or patients adequately informed about the procedures for HIV testing and the possible results or ramifications?

   ☐ yes ☐ no ☐ needs more work

7. What is the policy on confidentiality of test results? What staff or other persons are informed of HIV test results? Does your state have mandatory reporting of names or contact tracing policies?

   ☐ yes ☐ no ☐ needs more work

8. Are patients or clients being used for experimental drug or treatment protocols? If so, is this practice breaching federal or state laws? Are patients or clients coerced into giving consent for testing, treatment, experimental protocols, and other issues?

   ☐ yes ☐ no ☐ needs more work

Confidentiality

1. Does the agency or institutional policy have detailed procedures for protection of client records and confidentiality? What are the specific procedures for placing HIV serostatus in client files? Who is allowed to see the client file (clerical workers, staff members, physicians)?

   ☐ yes ☐ no ☐ needs more work

2. Does the agency or institution have penalties for breach of confidentiality? Are these penalties consistent with state law?

   ☐ yes ☐ no ☐ needs more work

3. What are your states' public health laws on management of recalcitrant individuals with dangerous communicable diseases? Who is vested with police powers to intervene on behalf of the public health in situations regarding recalcitrant individuals?

   ☐ yes ☐ no ☐ needs more work

Universal Precautions

1. What constitutes the agency's or institution's actual procedures for infection control practices of staff and clients? Universal precautions is a set of standards and procedures established by the U.S. Centers for Disease Control for all health care settings. Are the staff familiar with these guidelines and other documents aimed at protecting workers and clients from unnecessary risks associated with care and treatment?

   ☐ yes ☐ no ☐ needs more work

2. Are management staff aware of universal precautions and implementation of safeguards as a way of minimizing claims of liability from negligent actions?

   ☐ yes ☐ no ☐ needs more work

3. Are the necessary protective gear and equipment available and in place for emergency invasive procedures in institutions and agencies? Does the on-line staff member on wards, group homes, or day programs, also have access to this equipment? This protective equipment includes face masks, gowns, resuscitation devices, and other equipment.

   ☐ yes ☐ no ☐ needs more work

Intake & Assessments

1. Are patients and clients routinely asked information about their sexual lifestyles or drug use in order to assess for exposure to dangerous communicable disease, including HIV? Is this assessment completed in a sensitive and confidential manner? What procedures and counseling strategies are used to elicit information from parents or patients in a non-coercive manner?

   ☐ yes ☐ no ☐ needs more work

2. If a patient or client is identified with HIV, are they given special counseling, education services, and access to health services? All people are at risk for exposure to HIV, but are special intervention techniques used with clients who may be engaging in high-risk sexual behavior or IV drug use (vaginal or anal sex without a condom, exposure to infected blood and semen through openings in the skin or bodily tissues, or exchange of blood during IV drug use).

   ☐ yes ☐ no ☐ needs more work

3. Are staff, physicians, and psychiatrists up to date and educated on encephalopathy, mental illness or developmental disability caused by HIV infection of the brain or central nervous system? Are staff educated on how to determine whether encephalopathy or mental illness caused by HIV infection may be distinguished from other organic causes of mental illness or developmental disability?

   ☐ yes ☐ no ☐ needs more work

4. Are there or have there ever been patients or clients misdiagnosed with a mental illness or developmental disability when symptoms were actually caused by HIV infection? (It is important to note: HIV infection can cause mental illness in adults or developmental disability in children in the advanced stages of disease, but distinguishing the cause has important implications for care and treatment).

   ☐ yes ☐ no ☐ needs more work

5. Are there myths, stereotypes, or discriminatory actions on the part of staff and care-givers related to persons with HIV disease or AIDS? How can these persons best be educated about HIV disease, AIDS, and other related issues of sexuality and IV drug use?

   ☐ yes ☐ no ☐ needs more work

Access to Services

1. Do patients and clients receive regular medical checkups, and have access to needed medical and social care? Do patients and clients have access to drug treatments and protocols?

   ☐ yes ☐ no ☐ needs more work

2. Are physicians, nurses, psychiatrists and other staff knowledgeable about the interaction of psychotropic medications and drugs used to treat HIV disease and AIDS?

   ☐ yes ☐ no ☐ needs more work

3. Are patients or clients being denied admission to community social and residential services, institutional or other services, based on knowledge of their HIV status? Are these patients being denied for reasons related to their HIV status although this may not be explicitly acknowledged? (i.e., a client or patient is denied admission for reasons involving sexual behavior, suicidal behavior by engaging in high-risk sex, sexual orientation, and other reasons).

☐ yes ☐ no ☐ needs more work

4. Are patients or clients unfairly segregated or isolated based on HIV status? Are patients or clients segregated or isolated based on dangerous behavior that may injure or harm other staff or patients, including transmission of HIV?

☐ yes ☐ no ☐ needs more work

Education

1. Do staff receive regularly scheduled education about HIV disease and AIDS, psychosocial issues related to HIV, IV drug use, homosexuality, sexuality of persons with disabilities, and infection control practices? If so, how often and with whom? Are local AIDS service organizations called upon to provide educational services?

☐ yes ☐ no ☐ needs more work

2. Do patients receive regular education about safe sex, HIV disease and AIDS, IV drug use, sexuality, and health issues? Are the programs sensitive to the cognitive and emotional level of clients? Are the programs offered during a convenient time of the day when clients or patients are alert and easily available? Are the programs sensitive to concerns of parents and institutional policies without compromising the quality or adequacy of the programs?

☐ yes ☐ no ☐ needs more work

Other Issues

1. How are persons with mental disabilities who may have HIV treated in homeless shelters or other facilities in the community?

2. Is there legislation pending in your state regarding mandatory HIV testing of patients or clients in mental facilities, or facilities for persons with developmental disabilities or mental retardation.

3. Do you have knowledge of the various federal and state statutes in place to protect the legal rights of persons with disabilities, including persons with HIV disease or AIDS (see resources to have on hand).

4. What legal advocacy resources exist in your community that may assist you with these issues? Can a consortium of experts be compiled from various organizations such as Protection & Advocacy Systems, AIDS service organizations, American Civil Liberties Union, Legal Services Corporation, state AIDS taskforces, and other resources to assist you?

Notes

Resources to Have On-Hand

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